

HELP Committee Patient Stories: Drug Prices

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Piper Peltz, Clinton, TN: "I have a pacemaker and suffer from other conditions as well. I have to resort to taking my expensive heart medicines *every other* day. I'm on disability and it takes most of my check to buy my medication. I do not have good quality of life because I cannot take my heart medicine properly."

Helen Arnested, Tacoma, WA: "I have asthma, allergies and diabetes. My medicines cost more than my rent. I cannot afford to take them all the time, especially when I reach the donut hole. There is no reason why Americans have to pay such exorbitant costs for drugs, unless you take into consideration the extreme greed of the pharmaceutical and insurance companies."

Jon Pavlus, Worland, WY: "I've had diabetes for 52 years and in the last 6 years I've watched my insulin prices go from \$6.75 a vial to \$375 a vial. I'm on disability and I can't afford this. I need help."

Ed Sherowski, Rutland, VT: "My husband, Ed Sherowski, suffers from Primary Progressive Multiple Sclerosis. Historically there was no cure; he simply took mild pain medication to endure it all. Now there's a new drug that just came out; it will retail for \$65,000 per shot which he will need twice annually. Even with insurance, we cannot afford this drug, but Ed wants to live. The price is ridiculous. It will bankrupt us when he tries it. What can we do???"

Debra Sain, Conover, NC: "I'm on disability, and I have to take 24 different medicines for my condition. One of my medications is over \$600, and I don't have that kind of money. Now my physician wants me on Latuda, but I don't have \$1,200. I've had to stop taking some of my medicines at the expense of my health because I can't afford them. Now I feel like crap every day and I'm tired of it."

Suzanne Veltri, Gibsonia, PA: "I have Type 2 Diabetes which I am proud to say I have controlled since I was diagnosed. I knew one day I would need more than Metformin and that day is here. Now the choice is high glucose or meds I cannot afford. I am also one of those that has inherited high triglycerides. The new drug, Repatha, seems promising but I do not have \$2,000 a month for the drug. No matter how much I exercise and how well I eat my body is failing me slowly but surely. How sad that the drug companies are failing me as well."

Adalyn Watts, Atlanta, GA: "I have diabetes and use insulin. When my pre-filled syringes became too expensive, I switched to buying bottles and filling the syringes myself. But those still cost \$100 a bottle. I am on Medicare and Social Security. Social Security is my only income source. I get too much

money to qualify for Medicaid, but I cannot afford \$100 insulin plus some other lower cost medications and still buy food and pay rent.”

Carol Tanning, St. Paul, MN: "I have MS and there is no cure but there are drugs that can help the progression of brain lesions. The doctor recommended two drugs. The first one, Copaxane, was denied and the second drug was Tecfidera. The copay alone is \$2,800, I had to apply for grants to help. Something has to be done with our drug prices."

Deborah Throneberry, Louisville, KY: "I was given Spriva while in the hospital. I was given a prescription, and when I took it to Walgreens, I was told that the price was over \$300 for a month supply. I called the MFG to see if they had samples or coupons, and the answer was no. I called my doctor, and he had no samples either. I called Sure Care (Obama Care), and finally, I found a policy that could provide the medication for \$50."

Gail DeVore, Denver, CO: "I have had Type1 diabetes since 1972. I have seen the invention of home glucose meters, insulin pumps, better insulin, continuous glucose monitors (CGM), and many other new and advancing treatment options for type 1 diabetics. The ability to constantly monitor the status of our blood sugars is critical in saving our lives. However, it all comes with a very high price. A single bottle of insulin costs about \$350. Many diabetics need multiple bottles per month to simply stay alive. Supplies can also cost about \$10,000 on top of that. These costs are exorbitant. Considering the risks diabetics like myself face if they do not adequately monitor this condition, the costs is absolutely unacceptable. Something must be done to lower the cost of insulin and all medications!"

Chris Kasserman, Lisbon, ME: "I have a chronic disease which requires \$10,000 a month for drugs to treat the disease. If the price went down, it would leave money to get other treatments to help me manage my disease."

Gail Ribeiro, Pawtucket, RI: "It is not fair that we have to choose between buying food or paying for prescription drugs."

Angel Porche, Montegut, LA: "Being diagnosed with Rhumatoid Arthritis at 39 was pretty devastating. My doctor prescribed Humira to put it in remission. To my utter shock, I found out this wonder drug was \$3,200! So, needless to say, I went without this prescription for almost two years. I was in so much pain because I could literally feel my feet crippling. My husband went to all lengths to get Blue Cross insurance to get me the help I needed. I now have this wonder drug. Praise God! My immune system is getting stronger and I'm not as sick anymore. I feel so bad for the men and women out there that cannot get the help they need because of money. It's just wrong that the Big Pharmaceutical companies can charge that much money for one syringe of liquid."

Nicholas Schommer, Darien, WI: "I have COPD and Idiopathic Pulmonary Fibrosis. OFEV (Nintedanib) is \$2,500 copay with insurance. I got a grant for \$9,000 with Healthwell. It should help me out for about 4 months. \$2,500 is more than my SS check. This disease is taking me out very rapidly."

Jane Murrell, Mishawaka, IN: "I had a double lung transplant in 2014. I take about 25 different meds a day. One med is \$850. That's more than 50% of my social security. Something must be done!"

Claudia Parisi, New Milford, CT: "My husband uses an Advair Diskus inhaler which cost us \$75 with our insurance. When my husband lost his job several years ago, we struggled to pay the \$120 per month for the inhaler. Now, the same inhaler is over \$500 each. However, this spring my son-in-law found that he was able to purchase the exact same inhaler in Portugal for UNDER \$20. Why are Americans forced to pay three, four or five times the amount people in other countries pay? We need our elected officials to help us."

Scott, Utah County, UT: "I need a drug called Xyrem to sleep. Without it, sleep only happens every 3-5 DAYS and is filled with nightmares. I have to pay \$4,000 a week this drug. It's truly insane! I know that the drug company that makes this drug is in a court battle trying to prevent generics from being made. This drug is salt water based and I need it to live a normal life. There's no reason for it to be so unaffordable!"

Vallarie Pope, Braintree, MA: "I live on Social Security Disability Insurance and Medicare Part D. Even with Part D, my out-of-pocket costs for Lyrica, Advair, and other medications sometimes can be as high as \$450 a month. I have to live at my grandson's house and choose between the drugs I need and living expenses like food! Something has to change!"

Carolyn Onelager, Lawrence, KS: "My husband is on Advair for his paralyzed diaphragm. The cost is almost \$1,700 for a 3-month supply. Even with insurance, we're having to put at least \$500 on credit cards when we fill his prescription. It's ridiculous! Living with the uncertainty of how much the price will change year to year is a big stress on our family."

Iris Brickey, New Castle, VA: "I am a diabetic on 2 different types of insulin and other medications for cholesterol and high blood pressure. I paid \$10,000 for all of my meds last year combined. That's almost a third of my income and I just can't afford it."

Terry M., Homer, AK: "I had to change brands [because of costs]. The new brand did not work well, therefore I had to use twice as much. My life would be greatly improved if drugs were affordable."

Jennifer Smith, Chesterfield, NH: "I have Type 1 Diabetes, Rheumatoid Arthritis (RA) and lung disease. If it weren't for the Enbrel I take for RA, I would be in great pain in my joints and eventually die. I also would obviously die without the insulin I take. Embrel costs \$1,000 per weekly dose and my insulin costs \$700 for a months supply. In the past, I was without insurance and stopped taking Enbrel because of the cost. Because of this, my RA disabled me, limiting how much income I can make. Thankfully I am now on Medicare and Medicaid which helps, but I fear that cuts to those programs could really hurt me because the drugs I need to survive are so expensive."

Lawrence Schelero, Conway, SC: "I have been taking Glipizide for \$9 for 90 pills for over 1 year now. My doctor wants me to change to one of seven new drugs which cost between \$450 and \$750 for only 30 days. This is criminal."

